

NAVIGATING ADULT DISABILITY SERVICES AMONG LATINX CAREGIVERS OF  
YOUTH WITH AUTISM SPECTRUM DISORDER

by

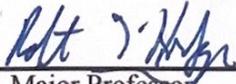
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May 2024

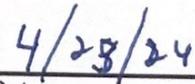
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Latinx caregivers of adolescents and young adults with autism spectrum disorder (ASD) face unique barriers in accessing adult disability services for their offspring. Barriers include not having access to resources in their first language, facing discrimination from professionals or service providers, and not having enough information about how to get a specific service. In this study, we examined the unique responses of 45 Latinx caregivers (primarily mothers) before completing a 12-week advocacy training program called ASISTIR. Results demonstrated significant positive correlations between participants' behaviors, comfort in advocating for services, and their sense of empowerment. Participants' disability advocacy was also related to their comfort and proficiency with the English language. Findings from this study shed light on the crucial role of designing culturally and linguistically appropriate resources and content that equips Latinx families in understanding and advocating for adult disability services in the United States. Implications for research and policy are discussed.

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NAVIGATING ADULT DISABILITY SERVICES

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YOUTH WITH AUTISM SPECTRUM DISORDER

by

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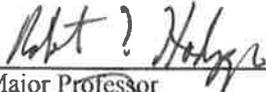
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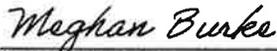
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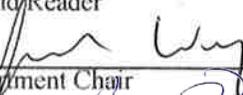
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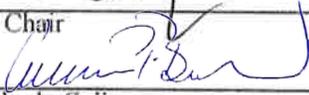
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## CHAPTER 1

### INTRODUCTION

For adolescents and youth with intellectual and developmental disabilities transitioning to adulthood can be complex and challenging. As they exit high school, students with disabilities must adjust to experiences beyond the academic setting, from finding a job tailored to their interests and skills to pursuing higher education opportunities or living independently (Taylor et al., 2017). As mandated by the Individuals with Disabilities Education Act (IDEA), transitioning from school to adulthood often requires extensive preparation for employment, independent living, and postsecondary education (Aleman-Tovar et al., 2022). Further, this process is rooted in continuous collaboration between students and their educators, caregivers, and others (Taylor et al., 2017). Of particular importance are the involvement and experiences of caregivers as they support their young adults in advocating for appropriate services (Skillern & Carter, 2021).

Although parental involvement is central in the transition planning process, many caregivers of transition-age youth with disabilities are unfamiliar with available services and supports for their offspring (Aleman-Tovar et al., 2022). In particular, caregivers of youth with autism spectrum disorder (ASD) may have difficulties accessing specialized services after high school, as they may no longer qualify to receive services under IDEA (Taylor et al., 2017)

Compared to their peers with other disabilities, young people with ASD are less likely to receive therapeutic services, including speech, physical, and occupational therapy after graduation, with barriers increasing for youth who have both ASD and an intellectual disability (Laxman et al., 2019).

To foster caregiver participation in the transition planning process, several trainings have been implemented to improve caregivers' knowledge, advocacy skills, and sense of empowerment (Aleman-Tovar et al., 2023). One such training, the Volunteer Advocacy Program-Transition (VAP-T), involved a 12-week intervention that supported parents of youth with ASD to advocate for adult disability services (Taylor et al., 2017). During each week of the training program, professionals with knowledge of adult services led a session on a specific transition topic, including on such issues as advocacy, Medicaid Waiver, Supplemental Security Income, housing/residential concerns, and person-centered planning (Taylor et al., 2017). Initial analyses indicated that, following the 12-week-long intervention, caregivers increased in their knowledge of adult services, advocacy skills, and feelings of empowerment, as well as in accessing services for their youth with disabilities (Taylor et al., 2017). Through this training, researchers hypothesized that parents of youth with disabilities who felt more comfortable advocating for their offspring were more successful in obtaining adult services (Taylor et al., 2017).

But such connections may not be present for all youth with disabilities. Of particular concern are the disparities in post-school outcomes for Latinx students with disabilities. Hispanic or Latinx refers to a person of Mexican, Cuban, Puerto Rican, Central or South American, or other Spanish origin or culture, regardless of race (U.S. Census Bureau, 2022). According to data from the U.S. Department of Education (2020), more than 20% of students aged 6-21 who are

diagnosed with intellectual disabilities, autism, or multiple disabilities are of Hispanic origin. Compared to their White, Non-Hispanic peers with disabilities, however, Latinx young adults with disabilities are less likely to receive postgraduation services such as competitive employment, resulting in dissatisfaction with the transition-planning process (Francis et al., 2018). Other experiences, including Latinx caregivers who have experienced discrimination on their immigration status may unintentionally limit their involvement in the transition-planning process, thereby limiting their access to knowledge about school-based transition planning and adult services for youth with disabilities (Aleman-Tovar et al., 2023).

Latinx youth and their families may also encounter barriers due to interacting with their providers in their second language or in adapting to different parental or cultural expectations (Francis et al., 2018). To understand the influence of these barriers, it is vital to consider the notion of acculturation. Acculturation entails “all the changes that arise following contact between individuals and groups of different cultural backgrounds” (Sam, 2006, p. 11). This process occurs when an individual or a group arrives at a new cultural context and interacts with novel attitudes, values, and behaviors (Berry, 2006). At an individual level, acculturation can be measured in terms of the orientation a person has towards their native group and the preservation of their heritage, or the orientation and involvement with the new culture, which may lead to the adoption of new cultural values, beliefs, and behaviors, including learning a new language or societal expectations (Berry, 2006).

Although programs such as the VAP-T have helped increase parental involvement in the transition-planning process, more needs to be known about the experiences of families from culturally and linguistically diverse communities, including Latinx caregivers (Aleman-Tovar et al., 2022). To support the involvement of Latinx families, a transition planning program based on

the ASSIST (Advocating for Supports to Improve Service Transitions) curriculum (Taylor et al., 2022) was culturally and linguistically adapted to increase the knowledge of adult disability services for Mexican-American families (Aleman-Tovar et al., 2023). Findings from this cultural adaptation helped inform and design a 12-week intervention known as ASISTIR or *Apoyando a nuestros hijo/as con la transición de la secundaria a la vida adulta*.

The ASSIST project was initially designed to expand the VAP-T, as the latter solely reflected information on adult disability services for one state. Because adult disability services may differ across the country, the project was delivered six times across three states: Illinois, Tennessee, and Wisconsin, with sessions occurring both in person and online (Taylor et al., 2022). The revision team included experts in ASD and adult services, disability advocacy groups, and parents. The team examined information about adult disability services and supports nationwide and determined issues that would differ based on state and location, allowing each site to tailor the content and information to their unique context (Taylor et al., 2022). To increase ASSIST's functionality across the country, the revision team incorporated a standardized curriculum and individualized learning objectives for each training session (Taylor et al., 2022). Findings from the adaptation of the VAP-T into ASSIST suggested that the program could be delivered with feasibility to support parents of youth with ASD as they navigate the adult disability service system across three states (Taylor et al., 2022).

The ASISTIR project, like the ASSIST and VAP-T programs, emphasizes the development of transition and adult disability services knowledge and the strengthening of parental empowerment and advocacy skills (Taylor et al., 2022; Aleman-Tovar et al., 2022). Given the unique needs of Latinx families, to become effective advocates, caregivers must understand the process of transitioning to adulthood, as well as special education and disability-

related laws (Goldman et al., 2020). Moreover, to access services for their offspring, Latinx caregivers must be confident in collaborating with school professionals and service providers and advocating for services for their offspring as needed (Goldman et al., 2020).

Along with the knowledge of and comfort in advocating for adult disability services, empowerment is another critical characteristic related to parent advocacy training (Goldman et al., 2020). When training programs are tailored to the needs and input of Latinx caregivers, parental participation, and empowerment increase (Aleman-Tovar et al., 2022). Through empowerment, caregivers gain confidence to become active participants in the lives of their offspring with disabilities and support them in reaching their goals (Rios & Burke, 2021). This sense of empowerment might differ across individuals, as it may either be a pre-existing attribute or may be developed during advocacy training (Goldman et al., 2020).

This study aimed to explore the unique experiences of Latinx parents of adolescents and transition-age youth with ASD prior to completing ASISTIR's 12-week advocacy training program. To this aim, we explored three main areas:

1. Compared which items within the domains of Knowledge, Advocacy Skills and Comfort, Advocacy Activities, Empowerment, and Access to Adult Services were more easy or difficult for Latinx caregivers. As well as determining the primary barriers in accessing adult disability services.
2. Analyzed whether any relations existed among different outcomes variables.
3. Determined whether differences exist in the knowledge, advocacy activities and comfort-skills, and sense of empowerment for Latinx caregivers who demonstrate different levels of English-language skills in speaking, reading, and writing.

By examining these key elements, this study explored the experiences of Latinx families as they navigate the terrain of disability advocacy, training, and support.

## CHAPTER II

### METHODS

#### *Participants*

Participants included 45 individuals who completed the ASISTIR pretest. Participants were mostly mothers (84%) of children with disabilities from the state of Illinois. Almost all participants were of Mexican origin (86%), and most (69%) were married. A large percentage (47%) reported annual incomes of 29,000 and below, and approximately 53% of respondents completed a high school or some college (see Table 1).

The offspring of these respondents were mostly male (82%) and between the ages of 12 and 14 (35%), who primarily had a diagnosis of Autism (84%), although many had co-occurring diagnoses of speech/language impairment (40%), or intellectual disability (32%) (see Table 1). Eligibility requirements included being Hispanic/Latinx parents or caregivers of adolescents/adults with autism spectrum disorder (ASD) who lived in the state of Illinois. Respondents were eligible to participate if their offspring was at least 12 years old. In order to become an attendee of ASISTIR, participants needed to agree to attend 12 weekly 2-hour synchronous online sessions and fill out a pre and post-test questionnaire prior to and after the training.

All respondents enrolled to take the ASISTIR training, with half taking the current training (i.e., fall, 2023), and the remainder to take the training in the spring of 2024. For this study, the two groups were combined. Respondents constituted Latinx caregivers of youth and adults with disabilities who completed a statewide, web-based survey. Of the initial sample (N = 63), 17 respondents were excluded if they left the survey blank or if they failed to answer more than 20% of the survey questions for each section.

**Table 1**

*Respondent Demographics*

<b>Characteristics</b>	<b>% (n)</b>
<b>Gender</b>	
Female	90.7% (39)
Male	9.3% (4)
<b>Role</b>	
Mother	84.4% (38)
Father	8.9% (4)
Legal Guardian	2.2 (1)
Other	4.4% (2)
<b>Marital Status</b>	
Married	68.9% (31)
Never married	8.9% (4)
Separated	13.3% (6)
Divorced	4.4% (2)
Widowed	4.4% (2)
<b>Race/ethnicity</b>	
Mexican	86.4% (38)
Puerto Rican	4.5% (2)
Central American	2.3% (1)
South American	4.5% (2)
Other	2.3% (1)
<b>Educational Background</b>	

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Some high school	22.2% (10)
High school or some college	53.4% (24)
College or Graduate School degree	24.4% (11)
Annual Income	
Less than \$15,000	23.3% (10)
Between \$15,000 – 29,000	23.3% (10)
Between \$30,000 – 49,000	37.2% (16)
Between \$50,000 – 69,000	4.7% (2)
Between \$70,000 – 99,000	11.6% (5)
<i>Offspring Demographics</i>	
Age	
Less than 12	13.2% (6)
12-14	35.5% (16)
15-17	24.3% (11)
18-22	17.7% (8)
Over 22	8.8% (4)
Gender	
Female	17.8% (8)
Male	82.2% (37)
Disability Type <sup>a</sup>	
Intellectual disability	31.7% (20)
Speech/language impairment	39.7% (25)
Autism spectrum disorder	84.1% (53)
Learning disability	36.5% (23)
Multiple disabilities	9.5% (6)
Blind/Visual impairment	4.8% (3)
Health condition	7.9% (5)
Deaf/hearing impairment	1.6% (1)
Emotional or behavioral disorder	28.1% (18)
Orthopedic impairment	6.3% (4)
Traumatic brain injury	1.6% (1)

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<sup>a</sup>Participants could select “all that apply.”

### *Procedures*

For a variety of reasons, researchers have found it difficult to recruit individuals from the Latinx community for intervention studies. To help recruit participants for this study we relied heavily on *personalismo* which entails building rapport and a relationship based in trust between potential participants and researchers (Aleman-Tovar et al., 2022). Specifically, participants were recruited through established connections between the authors of the project and Parent Training and Information Centers, disability agencies in Illinois (e.g., The Arc of Illinois), and word of mouth in parent support groups. A recruitment flyer with information on the study was disseminated in both English and Spanish, and each participant received a \$20 gift card after completing the pre-test survey.

To meet the needs of Latinx families of youth with ASD, project ASISTIR was culturally adapted from the transition program ASSIST (Taylor et al., 2017). Changes that occurred from the original ASSIST program included translating curriculum materials (e.g., survey) into Spanish; having a Spanish-speaking professional act as instructor; incorporating the cultural values of *familismo*, *colectivismo*, and *personalismo* into the curriculum; and including activities (e.g., ice breakers, and group discussions) to improve participants' knowledge, sense of empowerment, and advocacy (Aleman-Tovar et al., 2023). The study was approved by the institutional review board at Vanderbilt University and the University of Illinois at Urbana-Champaign.

The design for the ASISTIR program was a "wait-list control" design (Campbell et al., 1963). A wait-list control design involves randomly assigning participants into two groups: intervention and waitlist-control. In this design, the intervention group receives the training being evaluated first, while the waitlist-control group receives it after being placed on a "waitlist" for a

specific duration (Burke et al., 2016). For this study, the "pre-test" measures were combined for both the "experimental" group (i.e., those 23 participants who currently are attending the ASISTIR program) and the "control" group (those 22 participants currently waiting for the ASISTIR program to begin in the Spring of 2024). Thus, these findings relate to a relatively large ( $N = 45$ ) group of Latinx caregivers (mostly mothers), none of whom had taken the ASISTIR training at the time that they answered the questionnaire.

All participants of this study—both ASISTIR's experimental and control groups—filled out their pre-tests in RedCap by September 7<sup>th</sup>, 2023, before the experimental group began the ASISTIR program. The pre-tests of all 63 of the original participants were then downloaded into SPSS. After the director of the ASISTIR project (Dr. Meghan Burke) scored the Knowledge questionnaire for the total number of correct answers, we then cleaned, imputed, and combined sub-questionnaire measures (see below), before performing the final analyses for this study.

#### *Pre-Test Measure*

Before the training began, participants completed a pre-test that included the following sections based on prior studies on the English version of the ASISTIR project, called ASSIST (Taylor et al., 2022). The first section was related to training content (e.g., knowledge on adult services), while the remaining four sections used existing measures to assess the areas of comfort advocating, advocacy activities, sense of empowerment, and access to services. An acculturation scale was also utilized to assess participants comfort when reading, writing, and speaking in both Spanish and English.

**Demographics.** Participants were asked multiple-choice questions about their gender, race/ethnicity, educational background, role (e.g., mother, father, or legal guardian), annual income, as well as their offspring's age, gender, and disability type.

**Acculturation Scale.** This scale consisted of six items about the participants' comfort in reading, speaking, and writing in both Spanish and English. Participants rated their level of confidence when speaking, writing, and reading in both English and Spanish following a 4-Likert-type scale, ranging from 1 (*Poorly*) to 4 (*Excellent*) (Felix-Ortiz et al., 1994). In addition to separate English reading, writing, and speaking measures, we combined these three into a single measure of overall abilities in English. We also acknowledge that, while language ability is one important component of acculturation, other activities, behaviors, and beliefs, including preserving one's culture and interacting with the dominant culture (Davis et al., 2011) were not measured in this study.

**Knowledge of Adult Services.** *The Adult Services Knowledge Scale* (Taylor et al., 2017) consisted of 22 multiple choice questions related to knowledge on adult services including qualifications for SSDI, transition to adulthood resources (e.g., Vocational Rehabilitation), and knowledge on public housing. Examples of items included "How is a youth eligible for vocational rehabilitation services?" Each item had four potential response options but only one was correct. Each response was recoded as incorrect (0) or correct (1). Internal reliability for this scale was acceptable, with a Kuder-Richardson coefficient of 0.81 at pre-test.

**Advocacy comfort.** *The Advocacy Skills and Comfort Scale* (Taylor et al., 2017) is a 10-item scale that measures how comfortable and skilled participants perceive themselves to be advocating for their son/daughter. Examples of items include: "How able are you to advocate for your child's needs in trying to get adult services?". Each item was rated on a 5-point Likert scale from *not at all* to *excellent*. Scores were summed and averaged across the 10 items for each participant. The measure is reliable among Spanish-speaking, Latinx families of children with IDD

(Cronbach alpha = 0.92, Burke et al., 2016). Internal reliability for this sample was also high, with a Cronbach alpha of .91 at pre-test.

**Advocacy activities.** A 16-item measure (Aleman-Tovar, 2022) was used to analyze the extent to which parents/caregivers have engaged in advocacy behaviors. Items included, for example, the degree to which they have “Searched the internet to find agencies and/or services to meet your child’s needs” and “Talked with other parents (over the phone) about agencies and/or services to meet their child’s needs”. Each item was rated on a 5-point Likert scale from *not at all* to *very often*. Internal reliability was high, with a Cronbach Alpha of .943.

**Empowerment.** Originally created for parents of children with emotional disabilities, the *Family Empowerment Scale* (Koren et al., 1992) has also been used to measure empowerment as it relates to advocacy for parents of children with a range of disabilities (Burke et al., 2016; Taylor et al., 2017). Participants were asked to rate the degree to which they felt empowered to advocate for services for their offspring across 34 questions divided into 3 subscales. The Family subscale included 12 items related to Family Empowerment, including such items such as “I feel confident in my ability to help my son/daughter grow and develop.” This subscale showed high internal reliability with Cronbach’s alpha of .875 at pre-test. The Service system subscale also included 12 items related to attitudes, behaviors, and knowledge on services that professionals and agencies provide for caregivers. Items included “I know what steps to take when I am concerned my son/daughter is receiving poor services”, and Cronbach’s alpha equaled .882. Finally, the Community/Political subscale included 10 items related to collaborating with policy makers, agencies, and community members to access services for individuals with disabilities. Items included, “I help other families get the services they need”, and Cronbach’s alpha equaled

.849. Each item across the 3 subscales was rated on a 5-point Likert scale from 1 (*strongly disagree*) to 5 (*strongly agree*).

**Services Inventory.** Comprised of questions related to 10 adult disability services, the Services Inventory measures the number of met and unmet service needs (Summers et al., 2005). Items included “Is your son/daughter *currently* receiving SSI (supplemental security income).” Responses were dichotomous: “no” (0) or “yes” (1). If the offspring was not getting the service but currently needed it, participants were then asked why, with options ranging from “Applied for SSI but waiting for approval” to “Did not know about the service and/or how to get this service.” Items were summed to obtain the total number of received and needed services for all participants. For this study of youth with ASD, we examined service needs for the following services: 1) Medicaid/Medicare Health Insurance, 2) Supplemental Nutrition Assistance Program or SNAP, 3) SSI, 4) SSDI, 5) Medicaid Waiver, 6) Legal protection, 7) Medicaid Long Term Services and Supports, 8) Vocational Rehabilitation, 9) Special Needs Trust/ABLE Accounts, and 10) the Housing Choice Voucher. For each service, responses from the Kuder-Richardson coefficient were .78 at pre-test.

#### *Data Analysis*

After performing basic analyses related to respondent demographics (refer to Table 1), we performed subsequent analyses following the study’s three main goals. We began by examining items and determining scalability. We first performed a repeated measures ANOVA (for items rated on 1-5 scales) and McNemar’s tests (for correct-incorrect or yes-no items) to determine whether some items were easier or harder for participants within the domains of Knowledge, Advocacy Skills and Comfort, Advocacy Activities, Empowerment, and Access to Adult Services. Then, within each domain, we examined whether items were scalable, using

Kuder-Richardson tests (for yes-no or correct-incorrect items) and Cronbach's alphas for 5-point scales.

To analyze potential connections among variables, in a second set of analyses we correlated each of the pre-test measures (knowledge, comfort, advocacy activities, the 3 types of empowerments, and access to services). Finally, we correlated each outcome variable (knowledge, comfort, advocacy activities, and the 3 types of empowerments) using correlations (for continuous variables) to participant's perceived English proficiency. For example, did mothers who more often used English (vs. Spanish) relate to higher-lower scores on Knowledge, Comfort, Advocacy Activities, or Family, Service system, and Community/Political types of Empowerments. We examined the degree to which each of the English language skill items (and the total) were related to any of the outcome variables.

## CHAPTER III

### RESULTS

#### *Goal 1: Within-domain item comparisons*

Overall findings indicated that families had low levels of knowledge, with some individual items easier and harder for these participants. Out of 22 knowledge items, the average number of correct items was 24.75% (range from 4.4% to 53.3%). Comparing across items, those questions related to person-centered planning (53.3%), and guardianship (51.1%), were higher than those related to knowledge on eligibility criteria for the Supplemental Nutrition Assistance Program (4.4%), and legislation in post-secondary education (8.9%). McNemar's High vs Low item comparison  $p$ 's  $<.001$  (see Table 3).

Within items, we found that certain items were higher and lower. Using a repeated measure ANOVA, we found that in the family empowerment subdomain, items differed from one another so that the item *"I feel I am a good parent"* was higher than *"I feel my family life is under control."*  $F(11, 484) = 9.53, p <.001$ . Moreover, in the service system subdomain, the item *"When necessary, I take the initiative in looking for services for my son/daughter and family"* was higher than the question *"My opinion is just as important as professionals' opinions in deciding what services my son/daughter needs"*  $F(11, 484) = 12.69, p <.001$ . Finally, in the community/political subdomain, participants had a higher sense of empowerment for items

related to their impact on service access (e.g., “*I believe that other parents and I can influence on services for people with disabilities*”), compared to reaching out to lawmakers in their community (e.g., “*I get in touch with my lawmaker when important bills or issues concerning people with disabilities are pending*” or “*I have a good understanding of the services system that my son/daughter is involved in*”).  $F(9, 396) = 25.18, p < .001$ . (See Table 4). For the empowerment scale, we found that parents had higher levels of family empowerment (3.85) compared to service system empowerment (3.62) and community empowerment (2.4) (See Table 4).

Regarding advocacy activities, participants reported feeling like they “*Searched the internet to find agencies and/or services to meet your child’s needs.*” more than they “*Tried to get media attention (e.g., newspaper, television, radio) about disability services.*”,  $F(15, 660) = 26.63, p < .001$ . (see Table 5). In addition to advocacy activities, we also examined how questions within the advocacy skills and comfort domain differed from one another and found that items related to caregiver involvement in meetings with professionals (e.g., “*How able are you to effectively participate in meetings with providers/agencies/professionals*”) were higher than items related to their knowledge and rights in navigating adult services (e.g., “*How knowledgeable do you think you are about your rights in the adult service system?*”).  $F(9, 396) = 8.68, p < .001$ . (see Table 4).

Finally, as shown in Table 5, in regard to access to adult disability services, a higher percentage of individuals received Medicaid/Medicare Health Insurance (84%), and Supplemental Nutrition Assistance Program or SNAP (46%) compared to VR (8%), Special Needs Trust and/or ABLE accounts (3%), and the Housing Voucher (3%) (McNamar  $p$  of  $< .001$  for highest versus lowest items). Moreover, of 37 respondents who completed the Service Access

Measure, 51.4% (n=19) indicated that not knowing about a service or how to get it was a barrier to accessing adult disability services (refer to Table 5).

*Goal 2: Correlates of disability services knowledge, advocacy activities, comfort advocating, empowerment, and service access.*

As shown in Table 6, significant, positive correlations occurred between the scales of Advocacy skills and comfort and Community/Political Empowerment, as well as between Advocacy skills and comfort and Advocacy Activities. Correlations were in the moderate to high range ( $r$ 's from .333 to .638) between most outcome variables and the scales of Advocacy Activities, and Advocacy Skills and Comfort.

*Goal 3: Correlations between English Language Skill and Outcome Variables*

We examined differences in participants' comfort speaking, reading, and writing in English. Table 7 shows correlations between different outcome variables and participant's English language skills. Using  $p$  as the significance level, few significant correlations occurred. However, there were strong significant correlations between the level of comfort in speaking, reading, and writing in English and the Advocacy Skills and Comfort domain. Individual correlations ranged from .513 for Reading, .553 for Writing and .615 for Speaking. When combined together into a single measure the correlation was high ( $r = .667$ ) (see Table 7).

**Table 3**

*Knowledge high and low scores*

Scale	Correct Response Average	Item	Correct Response % (n)	High or Low
Knowledge	<b>24.75</b>	1. Person-centered planning	53.3% (24)	<b>H</b>
		2. Legislation	8.9% (4)	<b>L</b>
		3. Paperwork for Workforce	35.6% (16)	<b>H</b>
		4. Inclusive Employment	35.6% (16)	<b>H</b>
		5. Long term services and supports	8.9% (4)	<b>L</b>
		6. Medicaid services	22.2% (10)	<b>L</b>
		7. SSI	15.6% (7)	<b>L</b>
		8. Substantial gainful activity	20% (9)	<b>L</b>
		9. SSI and finances	20% (9)	<b>L</b>
		10. Policies for postsecondary ed.	22.2% (10)	<b>L</b>
		11. Vocational Rehabilitation	26.7% (12)	<b>H</b>
		12. SSDI	13.3% (6)	<b>L</b>
		13. SNAP	4.4% (2)	<b>L</b>
		14. Medicare Health Insurance	15.6% (7)	<b>L</b>
		15. Affordable Care Act	20% (9)	<b>L</b>
		16. Customized employment	44.4% (20)	<b>H</b>
		17. Home and Community waiver	20% (9)	<b>L</b>
		18. ABLE account	22.2% (10)	<b>L</b>
		19. Special Needs Trust	40% (18)	<b>H</b>

20. Public Housing	28.9% (13)	<b>H</b>
21. Guardianship	51.1% (23)	<b>H</b>
22. Housing voucher	35.6% (16)	<b>H</b>

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**Table 4**

*Empowerment and Disability Advocacy high and low scores*

Scale	Average score	Item	Mean (SD)	High or Low
Family Empowerment	<b>3.85</b>	<i>I feel I am a good parent</i>	4.43 (.779)	<b>H</b>
		<i>I feel my family life is under control</i>	3.19 (1.26)	<b>L</b>
Service System Empowerment	<b>3.62</b>	<i>When necessary, I take the initiative in looking for services for my son/daughter and family.</i>	4.09 (.985)	<b>H</b>
		<i>My opinion is just as important as professionals' opinions in deciding what services my son/daughter needs.</i>	2.76 (1.43)	<b>L</b>
Community/Political Empowerment	<b>2.4</b>	<i>I believe that other parents and I can influence on services for people with disabilities.</i>	4.11 (.875)	<b>H</b>
		<i>I get in touch with my lawmaker when important bills or issues concerning people with disabilities are pending</i>	1.91 (1.21)	<b>L</b>
Advocacy Activities	<b>2.24</b>	<i>Searched the internet to find agencies and/or services to meet your child's needs.</i>	3.27 (1.03)	<b>H</b>
		<i>Tried to get media attention (e.g., newspaper, television, radio) about disability services.</i>	1.37 (.853)	<b>L</b>
Advocacy Skills and Comfort	<b>2.82</b>	<i>How able are you to effectively participate in meetings with providers/agencies/professionals?</i>	3.13 (1.204)	<b>H</b>
		<i>How knowledgeable do you think you are about your rights in the adult service system?</i>	2.13 (.909)	<b>L</b>

**Table 5**

*Barriers to Accessing Services (Knowledge)*

Adult Services	Services Received % (n)	Remaining subjects (n)	Services Needed % (n)	Didn't know % (n)	Yes / No Knowledge Barrier
Medicaid or Medicare Health Insurance	83.8% (31)	6	16.7% (1)	0	No
SNAP	45.9% (17)	20	45% (9)	8.1% (3)	Yes
SSI	37.8% (14)	23	47.8% (11)	8.1% (3)	Yes
Medicaid Waiver (e.g., PUNS)	27% (10)	27	57.7% (15)	18.9% (7)	Yes
Legal protections	24.3% (9)	28	18.5% (5)	5.4% (2)	Yes
SSDI	13.9% (5)	31	57.7% (15)	53.3% (8)	Yes
Medicaid Long-term Services and Supports	13.5% (5)	32	41.9% (13)	18.9% (7)	Yes
Vocational Rehabilitation	8.3% (3)	33	40% (12)	18.9% (7)	Yes
Special Needs Trust / ABLÉ accounts	2.7% (1)	36	56.3% (18)	35.1% (13)	Yes
Housing Choice Voucher	2.7% (1)	36	12.1% (4)	8.1% (3)	Yes

**Table 6**

*Correlations between scores across domains*

	Knowledge	Advocacy Activities	Advocacy skills and comfort	Family Empowerment	Service System Empowerment	Community/Political Empowerment	Services Received
Knowledge	-						
Advocacy Activities	.379*	-					
Advocacy skills and comfort	.428**	.627**	-				
Family Empowerment	.141	.333*	.472*	-			
Service System Empowerment	.202	.386**	.521**	.891**	-		
Community/Political Empowerment	.246	.461*	.638**	.885**	.856**	-	
Services Received	.174	.385*	.176	.170	.229	.286	-

\* $p < 0.05$ , \*\* $p < 0.01$

**Table 7**

*Correlations between English proficiency and Outcome Variables*

	Knowledge	Advocacy Activities	Advocacy skills and comfort	Family Empowerment	Service System Empowerment	Community/Political Empowerment
Speak in English	.280	.314*	.615**	.242	.268	.291
Read in English	.276	.202	.513**	.145	.156	.175
Write in English	.373*	.217	.553**	.203	.257	.331*
Overall English Proficiency	.313*	.344*	.667**	.248	.284	.334*

\* $p < 0.05$ , \*\* $p < 0.01$

## CHAPTER IV

### DISCUSSION AND CONCLUSION

As one of the few studies to examine the knowledge, advocacy, empowerment, and experiences of Latinx caregivers in accessing adult disability services for their offspring, this study had three main findings, each of which has important research and policy implications.

#### *Adult disability knowledge, advocacy, empowerment, and service access*

First, Latinx participants demonstrated greater knowledge of person-centered planning and legal issues (e.g., guardianship). They reported lower scores on issues related to eligibility requirements to access nationwide programs (e.g., SNAP) or information on laws that support their offspring after high school. Interestingly, although participants scored lower on knowledge of requirements to qualify for the Supplemental Nutrition Assistance Program, almost half reported already receiving this service. Thus, it would be essential to assess the type of information participants may need when applying to certain disability programs. For instance, previous research has documented the knowledge of Latinx families of children and youth with disabilities as an area of need on themes related to special education knowledge, IDEA requirements, and specific law issues (e.g., the role of the school attorney) (Burke et al., 2020). Thus, this finding may indicate the pressing need for more training in areas related to federal laws and nationwide services to support Latinx caregivers of youth with disabilities.

In terms of empowerment, there were notable differences in the average scores for the three types of empowerments, including family, service system, and community/political, with the latter being the lowest. These findings are consistent with other studies that have found Latinx families are less likely to engage in community/political activities (Burke et al., 2021) compared to their non-Hispanic, White counterparts. The differences in high versus low scores within the service system and community/political domains were of particular relevance. Several of the low items were related to collaborating with lawmakers, navigating the service system, and feeling as if their opinions were just as important as those of professionals. Notably, in the disability advocacy domains, participants also reported low scores for items related to knowing about their rights in the adult service system and seeking disability services through media attention.

These findings are consistent with previous research on Latinx caregivers' experiences when collaborating with service providers, including not feeling seen or heard by providers and struggling to clearly explain their concerns due to differences in language (Coffield et al., 2021). Other studies also found that, for immigrant families of children and youth with disabilities, a lack of culturally responsive practices led to perceptions of discrimination and conflicts in provider/caregiver communication (Novoa, 2015). Thus, culturally tailored interventions and programs that meet the needs of the Latinx population are needed to mitigate disparities in this area (Aleman-Tovar et al., 2022). For example, previous work by Burke et al. (2016) on the feasibility of an advocacy program tailored to the unique needs of Latinx families found that after completing an advocacy training, participants' sense of empowerment increased as they learned how to advocate for their offspring's rights.

Another barrier to accessing adult disability services was the lack of knowledge on specific services and how to get them. Interestingly, of the ten services participants reported receiving or needing for their offspring, Medicaid/Medicare Health Insurance was the service most caregivers were currently accessing to compared to other critical transition services such as vocational rehabilitation (VR) services and the Housing Voucher. This is consistent with the low scores participants reported on feeling empowered to navigate the service system, including VR support. However, future research should also assess whether the services received and needed are culturally relevant to Latinx families to determine if certain services are more important than others (Povenmire-Kirk et al., 2010). For instance, some Latinx families may be more concerned about receiving information on financial support for their offspring rather than seeking options for them to live independently as in some cases it is not custom to leave home until marriage (Povenmire-Kirk et al., 2010). In addition, other challenges impacting the access to transition services for Latinx families may include providing specific citizenship documentation or acquiring a Social Security number to access VR services or participate in work-related activities, processes that may be tied to mistrust or fear of being further stigmatized by the system, in turn hindering Latinx participation in transition-related activities (Povenmire-Kirk et al., 2010). Future interventions should also assess whether specific post-school goals and needs are culturally appropriate and relevant for Latinx families (Magaña et al., 2020). Therefore, family input and needs regarding navigating the adult disability system should be further explored when designing intervention programs.

#### *Correlates among outcome variables*

For Latinx parents in this study, there were significant positive correlations between the scales of Advocacy comfort-skills and the Service and Community/Political empowerments.

These findings are consistent with previous research on advocacy programs tailored to meet the needs of Latinx families where participants' involvement in advocating for their offspring resulted in increased empowerment (Burke et al., 2016). However, it is still unclear if a greater sense of service and community empowerment leads to increased comfort in advocating or if, as caregivers develop advocacy skills and comfort, they feel more empowered to collaborate with service providers or participate in community/political issues (Ríos & Aleman-Tovar, 2022). Therefore, future research should focus on evaluating these results over time to determine the causality of effects between these variables.

#### *Linguistically appropriate practices*

In this study, we found that participants' English proficiency significantly correlated with their comfort and skills in advocating for adult disability services. Such findings regarding caregivers' comfort speaking, reading, and writing in English are consistent with findings on the experiences of Latinx families who have faced barriers to accessing services in their second language (Wilt & Morningstar, 2018). In general, across the entire sample, participants reported higher scores in speaking, reading, and writing in Spanish than in English. However, due to the lack of available adult disability services and materials in Spanish, caregivers who are not proficient in English may face additional challenges in their level of involvement in transition planning for their offspring, particularly when service providers and school professionals do not provide adequate translation services (Burke & Goldman, 2018). Further, studies examining the access to therapy needs between Latinx caregivers with different levels of English proficiency found that those with lower proficiency levels experienced greater barriers in accessing therapeutic services for their children with ASD compared to Latinx caregivers who demonstrated higher proficiency (Zuckerman et al., 2017). Therefore, future research should

focus on designing culturally and linguistically appropriate resources and content that equips Latinx families in understanding adult disability services in the United States, to increase their comfort advocating and being involved in activities to support their offspring with disabilities.

Although low levels of English proficiency constitute one part of the acculturation process, future research should also explore other aspects of acculturation, including preference for accessing services in one's native language (Xu et al., 2022) and evaluating the experiences of Latinx families when working with professionals in the United States who may share divergent cultural attitudes and beliefs regarding transition to adulthood (Wilt & Morningstar, 2018). Indeed, approaches that consider the unique cultural and linguistic needs of CLD families have been shown to lead to stronger collaborations between service providers, professionals, and families (Aleman-Tovar, 2022; Wilt & Morningstar, 2018; Burke et al., 2016).

#### *Implications for research and policy*

Overall, our findings have several implications for future research on cultural responsiveness. First, as one of the first studies examining the experiences of Latinx caregivers of youth and adults with ASD, findings from this study shed light on the barriers that Latinx families encounter as they navigate the adult service system in the United States. For example, future work on advocacy training should consider exploring barriers related to community and political experiences (e.g., the impact of discrimination and racism in looking for services and families' previous experiences with service providers) (Xu et al., 2022), as well as the unique cultural, disability, and familial attitudes and beliefs that are most prevalent in their native culture (Burke & Goldman, 2018). Practitioners should also consider working closely with caregivers, youth with disabilities, and disability advocates to design trainings that foster

collaboration and ensure themes within the training are relevant to Latinx participants (Kuhn et al., 2020).

Similarly, policymakers should consider working closely with the Latinx community and other families from culturally and linguistically diverse backgrounds to design community resources and services tailored to this population's linguistic and cultural needs (Burke & Goldman, 2018). Indeed, our study, as well as other interventions received in the same language as participants are a feasible way to increase access to services for Latinx families (Magaña et al., 2020). Future research should also examine the experiences of Latinx participants who are navigating a novel service system that may differ from that of their home country/culture and its impact in accessing adult disability services. As Whitehead et al. (2020) note, *acculturation* is also a multidirectional process in which two cultures intersect, sometimes leading to the internalizing of two cultural identities. This biculturalism has been linked to higher self-esteem, lower internalizing behaviors, improvements in family relationships, and protection against immigration-related stress (Whitehead et al., 2020).

### *Limitations*

Although this study contributes to the understanding of Latinx caregivers' experiences in advocating for their offspring's rights to services, there are important limitations worth noting. First, most participants in this study lived in one state (Illinois). Due to the study being limited to one location, future research should consider the experiences of Latinx families across other regions in the United States, including rural versus suburban and urban settings (Francis et al., 2020). Second, because the majority of participants were of Mexican origin or descent, it would be essential to consider recruiting Latinx participants from various ethnic and racial groups to gain a more diverse understanding of the cultural beliefs and experiences of the Latinx

community. Moreover, because the majority of participants' offspring were male, the generalizability of this study may be limited; thus, future studies should address differences in gender when accessing adult disability services.

Finally, although there were significant findings related to participants' comfort in reading, writing, and speaking in English, more needs to be known about other aspects of the acculturation process, including interacting with novel societal and cultural expectations, and preserving one's heritage in a new culture (Davist el al., 2011). Acculturation is crucial in understanding the barriers that Latinx caregivers have encountered in accessing disability services for their offspring (Malkoff et al., 2020). Thus, understanding the interplay between the American and Latinx cultures is crucial when designing training programs that are culturally and linguistically diverse and that address the concerns, expectations, and norms of Latinx communities concerning disability (Aleman-Tovar et al., 2022).

Still, even considering these limitations, these findings begin the process of understanding the unique experiences and needs of Latinx caregivers of adolescents and youth with ASD. By examining the impact of language and knowledge barriers – as well as their correlates with empowerment, service access, and advocacy- we begin to understand the supports Latinx caregivers need to be active participants in their offspring's transition to adulthood, as they advocate for appropriate services in the adult service system.

**Table 2***English and Spanish proficiency level*

Language Skill	English		Spanish	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Speaking	2.02	.876	3.56	.693
Reading	2.04	.903	3.59	.658
Writing	1.91	.900	3.50	.731

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